

Medical end-of-life decisions in neonates and infants in Flanders

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Summary

Background Paediatricians are increasingly confronted with end-of-life decisions in critically ill neonates and infants. Little is known about the frequency and characteristics of end-of-life decisions in this population, nor about the relation with clinical and patients' characteristics.

Methods A death-certificate study was done for all deaths of neonates and infants in the whole of Flanders over a 12-month period (August, 1999, to July, 2000). We sent an anonymous questionnaire by mail to the attending physician for each of the 292 children who died under the age of 1 year. Information on patients was obtained from national registers. An attitude study was done for all physicians who attended at least one death during the study period.

Findings 253 (87%) of the 292 questionnaires were returned, and 121 (69%) of the 175 physicians involved completed the attitude questions. An end-of-life decision was possible in 194 (77%; 95% CI 70·4–82·4) of the 253 deaths studied, and such a decision was made in 143 cases (57%; 48·9–64·0). Lethal drugs were administered in 15 cases among 117 early neonatal deaths and in two cases among 77 later deaths (13% *vs* 3%; *p*=0·018). The attitude study showed that 95 (79%; 70·1–85·5) of the 121 physicians thought that their professional duty sometimes includes the prevention of unnecessary suffering by hastening death and 69 (58%; 48·1–66·5) of 120 supported legalisation of life termination in some cases.

Interpretation Death of neonates and infants is commonly preceded by an end-of-life decision. The type of decision varied substantially according to the age of the child. Most physicians favour legalisation of the use of lethal drugs in some cases.

Introduction

Paediatricians are confronted increasingly commonly with end-of-life decisions in relation to extremely ill patients.^{1–7} Three main categories of such decisions were addressed in this study: the withholding or withdrawal of potentially life-prolonging treatments; the alleviation of pain and clinical signs with opioids in doses that could potentially shorten life; and the administration of drugs with the explicit intention of shortening the patient's life.

Data obtained from attitude studies and surveys of physicians across Europe show substantial variation in legal permissibility, physicians' attitudes, and actual practices as regards end-of-life decisions.^{1,8–10} Despite the importance of the difference between early neonatal and later deaths in mortality statistics and the institutional organisation of health care, nothing is known about the differences in end-of-life decisions between these two categories of deaths. Furthermore, there could be a greater tendency to withhold (or withdraw) treatment in children with congenital malformations.^{2,11} Most studies of medical practice at the end of life in neonates and infants are based on surveys of physicians.^{1,6–10,12} Because the physician is the unit of analysis, all such studies have failed to make reliable estimates of the frequency of decisions at the end of life. One Dutch study used the death-certificate method,² for which the denominator for frequency estimations is known. Consequently, this method is known to be the most reliable for frequency estimations. In studies based on hospital records, the denominator is

also the patient; however, information on end-of-life decisions is not always included.^{3,5,13–15} This study in Belgium used the same method as the Dutch study, but we investigated deaths over 12 months rather than 4 months and took into account clinical characteristics of the children. We also did an attitude study on the attending physicians in the death-certificate study.

The study had three aims: to assess the frequency of different end-of-life decisions for neonates and infants in Flanders, Belgium; to identify relevant clinical and demographic characteristics of these patients; and to examine the attitudes of physicians who care for these patients during the last stages of their lives.

Methods

Design and data collection

In Flanders, the physician who completes the death certificate reports the death to the Preventive and Social Health Care Division of the Ministry of Flanders. Clinical information on death certificates is anonymous at the time of registration at the ministry. Attending physicians could be identified for 292 of the 298 children who were born alive and died in Flanders within the first year of life over the period August, 1999, to July, 2000. In two cases the physician could not be identified, and in four the physician had moved abroad. For each of the 292 deaths, we sent by mail to the attending physician a questionnaire to be completed anonymously. The second part of the questionnaire was designed to investigate the physicians'

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attitudes towards end-of-life decisions. Physicians who certified more than one death were asked to complete this part only once.

The questionnaire had been used in a previous study;² it was culturally adapted for small differences between Dutch and Flemish. The first part (death-certificate study) consisted of 47 questions that aimed to identify different types of end-of-life decisions: withholding or withdrawal of potentially life-prolonging treatment; alleviation of pain, clinical signs, or both with opioids in doses with potentially life-shortening effect; and the administration of drugs in lethal doses. To identify the main end-of-life decision, a hierarchy was created in the questionnaire based on the actual practice and the life-shortening intention of the physician.¹⁶ Physicians were asked whether the decision was intended to hasten death and, in their opinion, by how much time life was shortened.

The second part of the questionnaire (attitude study) consisted of 18 questions, presented in a random order and to be scored on a 5-point Likert scale. Physicians were asked whether they agreed with statements on the task of the physician, their own behaviour, and professional and public control in relation to end-of-life decisions for neonates and infants.

Data were collected by anonymous questionnaire, based on the principles of the total design method.¹⁷ A week before the questionnaire was sent, the physicians received a letter from the Belgian Society of Paediatrics to emphasise the importance of their participation in the study. Up to three reminders were sent. One physician at each of the eight Flemish units of neonatal intensive care cooperated in the study (Neonatal Intensive Care Consortium). A complex mailing procedure, involving a legal attorney, was developed to ensure the anonymity of patients and the participating physicians. The Belgian Medical Disciplinary Board approved this procedure. The responding physician sent the questionnaire to the attorney in a prepaid envelope. The questionnaire data were linked to data on characteristics of the infants, obtained from the registry of births and deaths of the Ministry of Flanders, and from clinical information files, collected by the Flemish Centre for Study of Perinatal Epidemiology. The patients' characteristics recorded included age at death, gestational age at birth, and congenital malformations (classified as single/multiple and major/minor malformations, on the basis of the Eurocat list).¹⁸ Before the data file was given to the researchers, it was made anonymous by the attorney. For physicians who completed more than one version of the second part of the questionnaire, only the first to arrive was included. The Medical Ethics Committee of the Academic Hospital of the Vrije Universiteit Brussel approved the study.

Statistical analysis

95% CI were calculated to estimate the frequencies of the main end-of-life decisions. The observed proportions of the categories were treated as probabilities for a

multinomial distribution. χ^2 tests and two-tailed Fisher's exact tests were used to compare differences of distribution between cases with and without an end-of-life decision category, for age at death, gestational age at birth, presence of a major congenital malformation, and life-shortening intention of the physician ($\alpha=0.05$ level of significance). Cases for which no data were available on particular variables were excluded from the corresponding analyses. Kruskal-Wallis tests were used to compare the distribution of gestational age (in weeks) per type of end-of-life decision. Variables graded with the use of 5-point Likert scales were transformed to a 3-point scale.

Role of the funding source

Both funding sources supported the study after approval of the study design that was proposed by the investigators. They had no role in collection, analysis, or interpretation of data, or in the writing of the report. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

Results

The response rate for the death-certificate study was 87%; 254 questionnaires were returned, but one was excluded because the answers were incomplete. Demographic and clinical characteristics of the patients for whom responses were received (age at death, sex, multiple pregnancy, place and province of death, cause of death, gestational age at birth, and presence of congenital malformations) were similar to those of the overall study population (table 1). However, the 45 deaths for which no response was received differed from those with responses for place of death, gestational age at birth, and presence of major congenital malformations. Of the 253 deaths for which responses were available, 181 (72%; 95% CI 65.6–77.0) occurred in a neonatal or other intensive-care unit, 44 (17%; 12.9–22.6) in other hospital departments, and 28 (11%; 7.5–15.6) not in hospital (mainly at home or in day-care facilities).

In 59 (23%) of the 253 deaths for which responses were available, no end-of-life decision was possible because the death was sudden and unexpected; ten of these were of neonates younger than 7 days (8%; 3.8–14.0) and 49 were of infants aged 7 days to 1 year (39%; 30.3–48.0). End-of-life decisions were possible for 194 deaths (77%; 70.4–82.4), 117 before the age of 7 days (92%; 86.0–96.2) and 77 after that age (61%; 52.0–69.7).

Of the 194 deaths for which an end-of-life decision was possible, no decision was made in 51 (20% of the 253 study deaths; 14.0–27.2), and treatment was continued until death. In 143 (57%; 48.9–64.0) at least one end-of-life decision preceded death (table 2).

In all 194 non-sudden deaths (for which an end-of-life decision was possible), the main end-of-life decision was to withhold or withdraw treatment in 86 cases (44% of non-sudden deaths; 34% of all study deaths). In 40 cases

(21%; 16%, respectively), opioids were used in doses with a potentially life-shortening effect. In 17 cases (9%; 7%) lethal doses or lethal drugs were administered.

According to the physician, the extent of life-shortening was probably between none and less than 24 h in 81 (59%; 50.0–67.0) of the 138 deaths preceded by an end-of-life decision. In 31 (23%; 15.8–30.3), the estimated life-shortening was between 24 h and 7 days; in 26 (19%; 12.7–26.4), it was longer than a week. In 29% (15 of 51; three missing) of all patients from whom treatment was withdrawn, estimated life-shortening was longer than a week, compared with 13% (11 of 87; two missing) of all other patients for whom an end-of-life decision was made (χ^2 test, $p=0.021$; data not shown).

Of all deaths, an end-of-life decision was possible in 117 (92%) of early neonatal deaths (during the first week of life) and in 77 (61%) of the babies who died later (table 2). All cases of sudden infant death syndrome were included in the latter group.

Of all 194 non-sudden deaths, end-of-life decisions were made in 91 (78%) early neonatal deaths, compared with 52 (68%) later deaths ($p=0.134$). The difference between early neonatal and later deaths was most striking in the use of drugs. The proportion in which opioids in doses with a potential life-shortening effect were used was two times higher for deaths after day 7 of life than for early neonatal deaths (table 2, $p=0.012$). Lethal doses or lethal drugs were given in a significantly higher proportion of neonatal deaths than in the older group ($p=0.018$). Also, non-treatment decisions were made in a greater proportion of early neonatal than of later deaths ($p=0.039$).

In nearly half of all non-sudden deaths (85 [45%]), the baby had at least one major congenital malformation, and 49 (26%) were born before the 37th week of gestation with at least one major congenital malformation (table 3). For all non-sudden deaths ($n=194$), the median gestational age at birth was 34 weeks. Other than for age at death, no significant relation was found between gestational age at birth or presence of major congenital malformations and occurrence or type of end-of-life decision. The decision to withhold treatment was made more frequently in children who were born prematurely with major congenital malformations than in children without this combination ($p=0.045$).

Of the 17 cases in which lethal doses or lethal drugs were given, seven were born very prematurely, three before the 26th week of gestation. Six of those infants also had severe intracranial haemorrhages (grade 3 or 4 according to Papile), and the seventh had lung hypoplasia due to ruptured membranes. All three of the very premature infants had a major congenital malformation. Their ages at death ranged between 10 min and 1 h. Three infants had several congenital malformations, one had a lethal metabolic disease, one had suffered severe birth asphyxia, and the only two cases of postneonatal death were a sudden infant death and a child who died of an infectious disease associated with hydrocephalus.

	All deaths (n=298)	Response from physician (n=253)	No response from physician (n=45)	p*
Place of death				0.002
Hospital	259 (87%)	225 (89%)	34 (76%)	
Home	29 (10%)	18 (7%)	11 (24%)	
Other	10 (3%)	10 (4%)	0	
Age at death				0.059
Early neonatal death (<7 days)	144 (48%)	127 (50%)	17 (38%)	
Late neonatal death (7–27 days)	37 (12%)	34 (13%)	3 (7%)	
Postneonatal death (>27 days)	117 (39%)	92 (36%)	25 (56%)	
Sex				0.258
Male	169 (57%)	147 (58%)	22 (49%)	
Female	129 (43%)	106 (42%)	23 (51%)	
Gestational age at birth, weeks				<0.0001
<26	44 (15%)	36 (14%)	8 (18%)	
26–28	38 (13%)	38 (15%)	0	
29–31	20 (7%)	19 (8%)	1 (2%)	
32–36	60 (20%)	57 (23%)	3 (7%)	
≥37	134 (45%)	101 (40%)	33 (73%)	
Major congenital malformations				0.03
None	191 (65%)	160 (64%)	31 (69%)	
One	56 (19%)	44 (18%)	12 (27%)	
Several	48 (16%)	46 (18%)	2 (4%)	
Cause of death				0.07†
Perinatal cause (all)	131 (44%)	118 (47%)	13 (29%)	
Antenatal	37 (12%)	34 (13%)	3 (7%)	
During labour or birth	11 (4%)	9 (4%)	2 (4%)	
Neonatal	83 (28%)	75 (30%)	8 (18%)	
Congenital malformations	83 (28%)	69 (27%)	14 (31%)	
Sudden infant death	42 (14%)	31 (12%)	11 (24%)	
Other cause	42 (14%)	35 (14%)	7 (16%)	

Data on gestational age at birth were missing in two cases and on major congenital malformations for three cases. *Fisher's exact test for difference in distribution between cases in response and no-response groups. †For four categories: perinatal cause, congenital malformations, sudden infant death, and other cause.

Table 1: Demographic and clinical characteristics of neonates and infants who died during the study period

Table 4 shows the life-shortening intention of the physician, according to the type of end-of-life decision, for all 143 deaths preceded by an end-of-life decision. In 72 (50%) of these deaths, the physician had the explicit intention of hastening the death of the patient. In 45 (32%), the possibility that the life might be shortened was taken into account but life-shortening was not the aim. The explicit intention of hastening the death of the patient was reported for significantly more of the decisions to withdraw a possible life-prolonging treatment than for other end-of-life decisions ($p<0.0001$). Within the end-of-

	Number of infants (%; 95% CI*)			p†
	All deaths (n=253)	Age <7 days (n=117)	Age ≥7 days (n=77)	
No ELD	51 (20%; 14.0–27.2)	26 (22%)	25 (33%)	0.134
ELD	143 (57%; 48.9–64.0)	91 (78%)	52 (68%)	
Non-treatment decisions	86 (34%; 26.4–41.9)	59 (51%)	27 (35%)	0.039
Withhold treatment	32 (13%; 7.7–18.9)	23 (20%)	9 (12%)	0.169
Withdraw treatment	54 (21%; 15.1–28.6)	36 (31%)	18 (23%)	0.326
Alleviation of pain, signs, or both‡	40 (16%; 10.5–22.5)	17 (14%)	23 (30%)	0.012
Lethal (dose of) drugs administered	17 (7%; 3.5–11.7)	15 (13%)	2 (3%)	0.018

The denominator for all deaths is the total of 253 deaths studied; the denominators for the classification according to age are the numbers for which end-of-life decisions were possible (ie, non-sudden). *Exact multinomial estimates. †Fisher's exact test for significance of difference in distribution of cases with or without a category of end-of-life decision between early and later deaths. ‡With opioids in doses that might shorten life.

Table 2: Frequency of end-of-life decisions

	No end-of-life decision (n=51)	Non-treatment decision		Use of drugs		Total
		Withholding (n=32)	Withdrawal (n=54)	Alleviation of pain and/or signs (n=40)	Lethal dose/drug (n=17)	
Gestational age at birth, weeks*						
<26	9 (18%)	9 (28%)	4 (8%)	6 (15%)	3 (18%)	31 (16%)
26–28	6 (12%)	6 (19%)	11 (21%)	7 (18%)	4 (24%)	34 (18%)
29–31	6 (12%)	3 (9%)	2 (4%)	4 (10%)	4 (24%)	19 (10%)
32–36	12 (24%)	5 (16%)	16 (30%)	6 (15%)	1 (6%)	40 (21%)
≥37	18 (35%)	9 (28%)	20 (38%)	17 (43%)	5 (29%)	69 (36%)
Mean	32.9	30.8	33.5	32.7	30.8	32.5
Median (range)	34 (22–40)	29 (22–41)	34 (24–41)	34 (23–40)	29 (24–39)	34 (22–41)
Congenital malformations						
None	34 (67%)	13 (42%)	30 (56%)	19 (49%)	10 (59%)	106 (55%)
One	10 (20%)	7 (23%)	11 (21%)	10 (26%)	3 (18%)	41 (22%)
Several	7 (14%)	11 (35%)	12 (23%)	10 (26%)	4 (24%)	44 (23%)
p†	0.117	0.154	0.874	0.765	0.996	
Combination of prematurity and congenital malformations						
Combination	9 (18%)	13 (41%)	11 (21%)	10 (26%)	6 (35%)	49 (26%)
No combination	42 (82%)	19 (59%)	41 (79%)	29 (74%)	11 (65%)	142 (74%)
p‡	0.139	0.045	0.459	1.000	0.384	

Data were missing on gestational age for one case, congenital malformations for three cases; and combination of prematurity and congenital malformations for three cases. Three cases with one minor congenital malformation (EUROCAT list) were excluded. *Kruskal-Wallis test to compare the distribution by category of end-of-life decision $p=0.167$. † χ^2 test: significance of difference in distribution among cases of the given category of end-of-life decision versus the remaining cases (including the category No end-of-life decision). The total number of cases is 191. ‡Fisher's exact test, for combination of prematurity and presence of congenital malformations versus the absence of this combination.

Table 3: Presence and nature of end-of-life decision in relation to clinical characteristics of patients for the 194 deaths for which an end-of-life decision was possible

life decision category “use of drugs”, an explicit intention to hasten death was less common than a co-intention or no intention ($p=0.0001$). In 29 (51%) of these cases, the physician had no life-shortening intention.

The reasons for making an end-of-life decision were missing in five cases. Among the remaining 138 cases in which an end-of-life decision was made, the physician declared that there was no real chance of survival for the baby in 93 (67%; 95% CI 58.9–75.1). In 40 cases (29%; 21.6–37.3) there was no hope of a “bearable future”. In five cases, other reasons were indicated.

In the attitude study of the 175 physicians, 121 responded (response rate 69%). These physicians attended 211 (71%) of all deaths in the year studied. Of the 121 physicians who completed the additional attitude questionnaire, 95 (79%; 70.1–85.5) thought that the task of the physician sometimes includes the prevention of unnecessary suffering by hastening death (table 5). One in eight physicians thought that termination of the life of a

newborn infant is not one of the tasks of a physician. Fewer than one in ten would not participate in any form of termination of life of neonates. As for the type of decision, more physicians were prepared, in some cases, to make a non-treatment decision rather than to use lethal drugs (111 [92%] vs 82 [68%]). 69 (58%; 48.1–66.5) physicians thought that the law should be adapted, making termination of life legally possible in some cases. One in five disagreed with this statement. Large majorities of the physicians agreed that continuation of treatment is not always in the interest of the child, that considerations about expected quality of life can be taken into account in decision-making, and that the parents' wishes can be taken into account in deciding on non-treatment.

Discussion

This death-certificate study investigated the frequency of end-of-life decisions in a population of deaths of neonates and infants over a period of 1 year. Despite the illegal nature of some of the medical practices concerned, the response rate was high and the conclusions are valid for the entire population. Nevertheless, deaths in hospital and those of children born at low gestational age or with major congenital malformations were somewhat under-represented in the non-response group. We cannot, therefore, exclude a potential bias in the results, arising from small overestimation of end-of-life decisions.

The attitude survey had a lower response rate, probably because physicians who were asked about more than one baby who had died were requested to complete this part only once. Thus, some of the physicians could have been tempted not to complete it at all. Further limitations of the study are its retrospective nature and the fact that findings are based on the perception of the physician and not on

Life-shortening intention of physician	Non-treatment decision		Use of drugs (n=57)*
	Withholding (n=32)	Withdrawal (n=54)	
No intention	11 (34%)	5 (9%)	29 (51%)
Co-intention†	8 (25%)	7 (13%)	11 (19%)
Explicit intention	13 (41%)	42 (78%)	17 (30%)
p‡	0.379	<0.0001	0.0001

*When the physician had no intention to shorten the life of the patient or the aim was also to alleviate pain, we defined the use of drugs as alleviation of pain and/or signs with opioids in doses with a potential life-shortening effect (n=40). When the physician had an explicit life-shortening intention we defined the use of drugs as lethal (dose of) drugs administered (n=17). †Life-shortening was not the primary aim of the physician. ‡ χ^2 test: significance of difference in distribution among cases of the given category of end-of-life decision versus the remaining cases. The total number of cases in each comparison is 143.

Table 4: Nature of end-of-life decision in terms of life-shortening intention of physician for the 143 deaths in which an end-of-life decision was made

Statement	Agree or strongly agree	Indifferent	Disagree or strongly disagree
Task of the physician			
From an ethical point of view, physicians who assist in terminating the lives of newborn infants are wrong.*	6 (5%)	15 (13%)	99 (83%)
It is not the task of the physician to contribute to the termination of life of a newborn infant.*	14 (12%)	19 (16%)	87 (73%)
The task of the physician sometimes includes the prevention of unnecessary suffering by hastening death.	95 (79%)	17 (14%)	9 (7%)
Physicians' behaviour			
I would not participate in any form of life termination in neonates.	10 (8%)	18 (15%)	93 (77%)
In some cases, I would be prepared not to treat a newborn infant any longer.	111 (92%)	4 (3%)	6 (5%)
In some cases, I would be prepared to shorten the terminal suffering of a newborn infant by using lethal drugs.*	82 (68%)	19 (16%)	19 (16%)
Professional and public control			
The law should be adapted so as to make termination of life possible in some cases.*	69 (58%)	27 (23%)	24 (20%)
I would complain to professional authorities against colleagues who assist in terminating the lives of newborn infants.	2 (2%)	10 (8%)	109 (90%)
Reasons for end-of-life decisions			
In some cases care provided to a newborn infant with a serious disorder is undesirable.†	80 (68%)	21 (18%)	18 (15%)
Continuation of treatment is not always in the interest of the child.*	112 (93%)	5 (4%)	3 (3%)
Considerations about expected quality of life can be taken into account in decision-making.*	106 (88%)	11 (9%)	3 (3%)
The parents' wishes can be taken into account in decisions to treat or not to treat.*	112 (93%)	8 (7%)	1 (1%)

Data are number and percentage of physicians. *Data missing for one case. †Data missing for two cases.

Table 5: Attitudes of physicians towards end-of-life decisions in neonates and infants (n=121)

other carers or the parents. However, the medical act and the intention of the physician form a firm basis for studies on the frequency of end-of-life decisions.^{2,11,19,20} The frequencies of end-of-life decisions in neonates and infants were combined with data on the clinical profiles of the patients, obtained from the registry of births and deaths. We were therefore able to find out relevant characteristics of the patients.

In Flanders, end-of-life decisions are an integral part of medical practice in critically ill neonates and infants: 74% of all non-sudden deaths were preceded by an end-of-life decision. In the physicians' opinion, life was shortened by less than a day in 59% of cases, and end-of-life decisions in neonates and infants were apparently made in most cases in the very last stage of life, as has been found in other studies.^{2,13} Non-treatment decisions made up the largest proportion of end-of-life decisions. Non-treatment decisions are an accepted part of medical practice, but the use of lethal drugs in minors is illegal in Belgium. Nevertheless, this end-of-life decision was reported for 17 (9%) non-sudden deaths. Lethal drugs were mainly used in three clinical situations: very premature infants with poor neurological outcome owing to intracerebral haemorrhage; infants with several congenital malformations, who generally are severely handicapped and have poor quality of life; and premature infants with major congenital malformations. Infants of the last group lived for only a very short time, which suggests that decisions not to start treatment were made antenatally. In general, the frequencies of end-of-life decisions in Flanders are similar to those found in the only comparable study in the Netherlands.²

We found substantial differences in the use of lethal drugs according to age at death: the proportion of deaths in which they were given was five times higher for early neonatal deaths than for later deaths. No other study has reported this important difference. The difference is unlikely to have any relation to a lower moral status being ascribed to all neonates, sound or not. One possible

explanation is that the most critical disorders are apparent in the early neonatal phase and mostly from the moment of or before birth. In these children, low chances of survival can be estimated early, leading to an end-of-life decision, possibly even in the delivery room.⁴

Some suggest that there is a greater tendency for non-treatment decisions in newborn infants with congenital malformations.^{2,11,21} In our study, end-of-life decisions were not made more frequently for children with congenital malformations, although the withholding of treatment was more commonly found in children with the combination of major congenital malformations with prematurity. Further research into the clinical characteristics of patients is needed to elucidate the relation between type of end-of-life decision and specific characteristics.

We found that about three in four physicians who are confronted with critically ill neonates and infants are willing to participate in certain forms of life termination in these children. The findings raise the issue of the underlying values and moral judgments of the physicians. The main reasons for shortening of the neonate's life were the absence of real survival chances (67% of the end-of-life decisions) and, if the baby survived, an expected very poor quality of life (29%). The agreement on the attitude statement that continuation of treatment is not always in the interests of the child (93%) suggests that the physicians subscribe to a best-interest standard.²² That standard is commonly accepted in medical practice as the basis for the withholding or withdrawal of neonatal care.¹¹ The vast majority of the physicians also appeared to accept a quality-of-life ethic, as shown by the agreement on the acceptability of quality-of-life considerations (88%). The agreement that the wishes of the child's parents can be taken into account in decisions on whether or not to treat (93%) probably reflects the idea that the child's representatives are the best judges of what is in the child's best interests or perhaps that the parents' interests count in an independent way.²³

Nearly 70% (82) of the physicians questioned in our study had either used lethal drugs for this purpose or could conceive of situations in which they would use them. A similar proportion was found in the Netherlands.^{2,21} The Euronc study (not including Belgium) showed that the administration of drugs with the aim of life termination in neonates was reported in substantial rates in the Netherlands and France, in contrast to other European countries.^{1,8,9} The finding for Flanders might be explained by the majority opinion that the prevention of unnecessary suffering is a professional task (79%). Harris has pointed out that prevention of unnecessary suffering in the neonate sometimes justifiably demands use of lethal drugs and that non-treatment unnecessarily prolongs suffering.²⁴ Judgments that life itself is not always in the child's best interests could also explain the high frequencies of end-of-life decisions explicitly intended to shorten life. This finding should not obscure the fact that, in many cases, the physicians complied with a commonly accepted version of the doctrine of double effect (justifying life-shortening as a predictable but unintended consequence of pain and symptom management; 51% of cases in which drugs were used). The physicians were not, however, asked about the ethical doctrine they had applied in particular cases; their statements about what they did and the intention they had were used to classify their actions according to the presumptions of the doctrine of double effect. The group of physicians who declared that they additionally had the intention to shorten life might have believed that they were complying with these doctrines, although in fact they were not.

For most countries in the Euronc study, considerations about legal constraints were rated as less important in decision-making than other considerations such as the presence of mental disability.¹⁰ In the absence of legal regulations, physicians involved in the care of dying neonates and infants have developed their own professional and ethical standards. We found that most of the physicians in this study favoured a change in the law, making termination of life possible. Unlike the recent process that led to the current law on euthanasia in Belgium, in this very difficult matter of end-of-life decisions in incompetent patients, evidence is found that the medical profession in Flanders supports a change in the law in consistency with their viewpoints and actual practice.

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Contributors

All authors and members of the Neonatal Intensive Care Consortium contributed to design and implementation of the study, analysis of data, and writing of the report, and have seen and approved the final version.

Conflict of interest statement

We declare that we have no conflicts of interest.

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